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Delivering the People with Arthritis Can Exercise (PACE) Program: A Report Prepared for the

Kansas Department of Health and Environment/Arthritis Foundation Arthritis Steering

Committee.

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Executive Summary

This report details the evaluation of the People with Arthritis Can Exercise (PACE) program offered through the Kansas Chapter of the Arthritis Foundation. The original purpose of this evaluation was fourfold:

- (1) To determine the number and representativeness of individuals who participated.
- (2) To determine the effect of the program on physical, psychological, and social function.
- (3) To determine if the PACE programs were being delivered as intended.
- (4) To determine if the PACE programs were successful in promoting adherence to the physical activity program over a 6-week period.

Our first finding during this evaluation was that the number of PACE programs and individuals within those programs was insufficient to allow for a valid evaluation. In consultation with the leaders of the Kansas Department of Health and Environment/Arthritis Foundation Arthritis Steering Committee the purpose of our evaluation shifted from examining the effectiveness of PACE programs to investigating the State's capacity for delivering PACE programming and, in essence, to determine why PACE programs were not being initiated even though program leaders were being trained. To achieve this purpose we compared the personnel responsible for programming, the fiscal environment, and the promotion details of Arthritis Foundation Chapters in Kansas, Missouri, Nebraska, and to a limited extent Iowa. The results revealed that PACE programs have been difficult to implement in Kansas, Iowa, and Nebraska. Both Missouri Arthritis Foundation Chapters were far more successful in implementing programs within their service areas. Based upon our findings we recommend that the capacity of Kansas to implement

PACE programs could be improved with two basic steps. First, the responsibility to develop and implement self-management programs should be distributed across a committee of volunteers led by the current paid Program Director rather than resting solely on a single paid staff member—as is the current situation. Second, the promotion of PACE programs within communities should be facilitated and supported by the Arthritis Foundation rather than leaving it to newly trained program leaders who are ill equipped to recruit participants.

Delivering the People with Arthritis Can Exercise (PACE) Program: A Report Prepared for the Kansas Department of Health and Environment/Arthritis Foundation Arthritis Steering

Committee.

This report details the evaluation of the People with Arthritis Can Exercise (PACE) program offered in three Kansas counties through the Kansas Chapter of the Arthritis Foundation. The original purpose of this evaluation was fourfold:

- (1) To determine the number and representativeness of individuals who participated.
- (2) To determine the effect of the program on physical, psychological, and social function.
- (3) To determine if the PACE programs were being delivered as intended.
- (4) To determine if the PACE programs were successful in promoting adherence to the physical activity program over a 6-week period.

Unfortunately, during the proposed evaluation period no viable PACE programs were implemented within the designated counties. The evaluation was then expanded to include any current PACE programs initiated or offered across the state. We again found no viable programs. This situation occurred even though PACE instructors were being trained. In consultation with the leaders of the Kansas Department of Health and Environment/Arthritis Foundation Arthritis Steering Committee the purpose of our evaluation shifted from examining the effectiveness of PACE programs to investigating the State's capacity for delivering PACE programming and, in essence, to determine why PACE programs were not being initiated even though program leaders were being trained. One way to understand the capacity of Kansas to offer such programs is to compare it with other states that have experienced success in offering the PACE programs.

Members of the Steering Committee suggested that Missouri could provide a viable comparison. It was also suggested that other states more similar in size to Kansas could be included in the comparison. To achieve our purpose an evaluation frame of questions was developed as follows:

- 1. What is the structure of the state's Arthritis Foundation?
- 2. Who is responsible for self-management programming?
- 3. Do you have a system for evaluating your programs?
- 4. Do you have an exercise or other volunteer committee?
 - a. Do they actively do site visits and promotion?
- 5. Determine the delivery of PACE programs in Kansas, Nebraska, Iowa, & Missouri
 - a. Document the number of PACE instructors that have been trained.
 - b. How many PACE trainings have been completed since January 2001?
 - c. How many potential PACE leaders have been trained since January 2001?
 - d. What mechanisms were used to get programs started?
 - e. How many PACE classes have started since January 2001?

The results are organized by state to allow for comparison of the personnel responsible for programming, the fiscal environment, and the promotion details of Arthritis Foundation Chapters in Kansas, Missouri, Nebraska, and to a limited extent Iowa. We collected all information from the respective Chapters prior to September 2002 through personal interviews and print and Internet materials supplied.

State Capacity for Delivery 6

Kansas

Total Population: 2,477,574

Projected population with arthritis: 403,000 (16.27%)

1. What is the structure of the state's Arthritis Foundation?

Kansas is a contribution-based Chapter, which means it relies mainly on private donors and fund-raisers for economic support. A single office provides service for the entire state excluding most of Johnson and Wyandotte counties (covered by the KC metro/Western Missouri Chapter).

2. Who is responsible for self-management programming?

The PACE program is under the supervision of the Chapter's Program Director. This Program Director is responsible for all self-management programming, as well as other tasks for the Chapter. The Foundation also has a health promotion committee that oversees programming, but it has not been involved in developing sites or delivering the PACE program.

3. Do you have a system for evaluating your programs?

Typical evaluation of all self-management programs is based on a 'post-only' assessment of participants. In this type of evaluation the leader or a volunteer administers a questionnaire at the conclusion of the program. In addition, some programs are evaluated quarterly, and others are evaluated semi-annually.

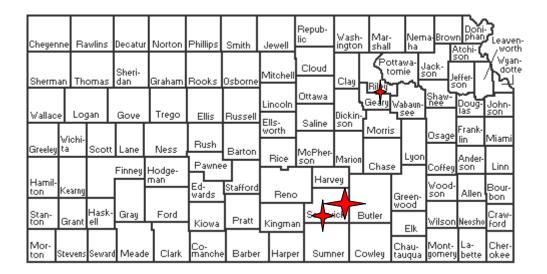
4. Do you have an exercise or other volunteer committee? a. Do they actively do site visits and promotion?

The Chapter does have a health promotion committee. The committee members do not actively complete site visits or engage in promotion. The Chapter does not provide assistance for promoting individual programs. Any promotional activities are left solely to the PACE instructors and facilities that offer the program. A number of Instructors who were trained in Kansas commented that the PACE program leader trainings did not include extensive information regarding how to promote or recruit participants for the program.

5. Determine the delivery of PACE programs in Kansas

Since the beginning of 2001, two PACE program leader trainings were held (an additional training has been completed since the completion of our project). Approximately 12 individuals were trained to lead PACE classes. Unfortunately, the leaders rarely initiated new PACE programs. At the time of this report only 2 PACE programs were being offered in Wichita and 1 program (with one participant) was being offered in Manhattan, it has since been discontinued (See Map). In sum less than 20 participants had been involved in PACE programs.

Distribution and Number of PACE Programs In Kansas



State Capacity for Delivery 9

Iowa

Total Population: 2,776,755

Projected population with arthritis: 477,000 (17.18%)

NOTE: It was difficult to obtain some of the information we required from the Iowa Chapter of the Arthritis Foundation. They were reluctant to provide specific numbers or information regarding their PACE programs without permission from the National office. Repeated attempts on our part to contact Shannon Mescher, V.P. of programs (Health Promotion) in the National Arthritis Foundation office were unsuccessful and specific permission was not obtained. As a result some of the information regarding the state of affairs in Iowa was not available.

1. What is the structure of the state's Arthritis Foundation?

Iowa is a contribution-based Chapter, which means it relies mainly on private donors and fundraisers for economic support. A single office provides service for the state.

2. Who is responsible for self-management programming?

The PACE program is under the supervision of the Chapter's Education Coordinator. The Coordinator is responsible for all self-management programming, as well as other tasks for the Chapter.

3. Do you have a system for evaluating your programs?

Although, the Iowa office personnel suggested that they evaluated their programs, details on the policy and procedures were not provided to us.

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4. Do you have an exercise or other volunteer committee? a. Do they actively do site visits and

promotion?

They do not have a committee responsible for self-management programs.

5. Determine the delivery of PACE programs in Kansas

The Iowa Chapter had completed two PACE trainings since January 2001, and had 20 possible

instructors from these trainings. Like Kansas, the Iowa Chapter left it to the instructor and

facility to promote the PACE program. However, we do not currently have information

concerning the dispersal of classes in Iowa. Qualitatively, it seemed that Iowa was not

successfully implementing viable PACE programs.

Nebraska

Total Population: 1,578,385

Population with arthritis: 260,000 (16.47%)

1. What is the structure of the state's Arthritis Foundation?

Nebraska is a contribution-based Chapter, which means it relies mainly on private donors and

fund-raisers for economic support. A single office provides service for the entire state similar to

the Foundation Chapters in Kansas and Iowa.

2. Who is responsible for self-management programming?

The PACE program is under the supervision of the Chapter's Program Director. This Program

Director is responsible for all self-management programming, as well as many of the day-to-day

tasks associated with running the Arthritis Foundation Chapter office. The Program Director

indicated that she did not have much time to focus on the implementation and delivery of PACE programs.

3. Do you have a system for evaluating your programs?

The Nebraska Chapter did not currently have a system for evaluating their programs, but was in the process of developing a policy for evaluation for future use.

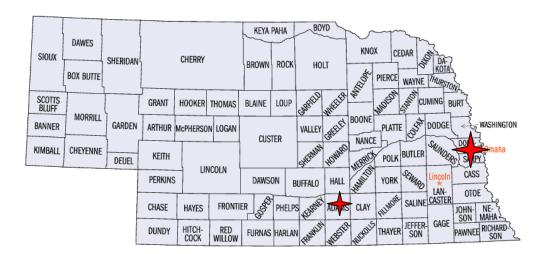
4. Do you have an exercise or other volunteer committee? a. Do they actively do site visits and promotion?

They do not have a committee responsible for self-management programs.

5. Determine the delivery of PACE programs in Kansas

Since the beginning of 2001, a single PACE program leader training was held. Approximately 8 individuals were trained to lead PACE classes. Similar to Kansas and Iowa, the proportion of leaders who initiated programs was very low (i.e., about 25%). At the time of this report only 2 PACE programs were being offered in Nebraska (See Map). In sum less than 20 participants have been involved in these PACE programs.

Distribution and Number of PACE Programs In Nebraska



Missouri

Total Population: 5,117,073

Population with arthritis: 856,000 (16.73%)

1. What is the structure of the state's Arthritis Foundation?

Although, the Missouri Chapters of the Arthritis Foundation are also contribution funded they have additional programming support from the Missouri Arthritis Program that is funded by the CDC (since 1998) and the state (since 1985). This support is very different from those described in Kansas, Iowa, and Nebraska. Due to the large difference in population (about twice as many people in Missouri when compared to the other three states), Missouri uses two Chapter offices. The first is the Western Missouri/Kansas City Metro Area Chapter located in Kansas City, Missouri. The second is the Eastern Missouri Chapter located in St. Louis, Missouri. Further, each Chapter is responsible for the training for, and implementation of, self-management programs. Each utilizes a state office to conduct the evaluation of their programs.

2. Who is responsible for self-management programming?

The PACE program is under the supervision of the Chapters' programs and services committee.

This committee is primarily volunteer led and operated and is responsible for upkeep of the self-management programs. The programs and services committee is also integrated with seven

Arthritis Centers housed within local hospitals across the state. The committee is also responsible for advertising and promotion of each new and ongoing program. The committee ensures that each program is well advertised and promoted.

3. Do you have a system for evaluating your programs?

Similar to Kansas, typical evaluation of all self-management programs is based on a 'post-only' assessment of participants. In this type of evaluation the leader or a volunteer administers a questionnaire at the conclusion of the program. In addition, some programs are evaluated quarterly, and others are evaluated semi-annually. A state office provides assistance and guidance for evaluation.

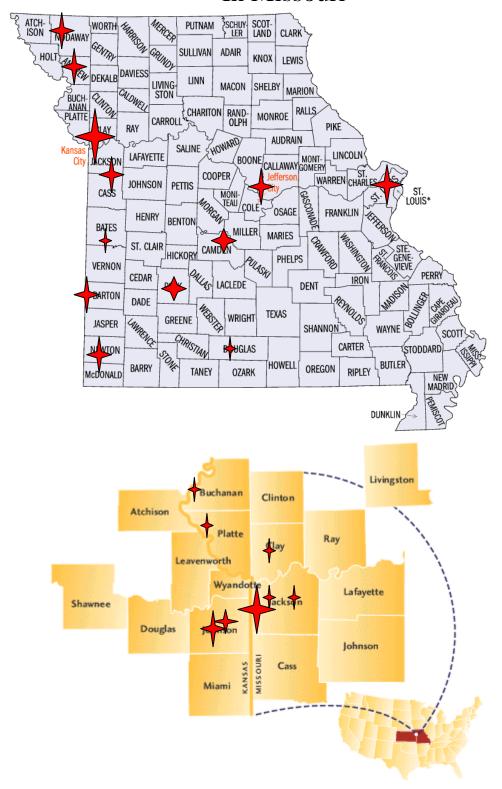
4. Do you have an exercise or other volunteer committee? a. Do they actively do site visits and promotion?

Missouri utilizes a programs and services committee that is actively involved and in all aspects of programming (See point 2 above).

5. Determine the delivery of PACE programs in Kansas

Since the beginning of 2001, 4 PACE program leader training were held. Approximately 35 individuals were trained to lead PACE classes. Approximately 50% of the leaders who were trained initiated and delivered a PACE program. At the time of this report 20 PACE programs were being offered across Missouri (See Map). Approximately 200 participants have been involved in these PACE programs.

Distribution and Number of PACE Programs In Missouri



Summary and Conclusions

The data collected during this evaluation suggest that PACE programs have been difficult to implement in Kansas, Iowa, and Nebraska. In contrast, both Missouri Arthritis Foundation Chapters were successful in implementing programs within their service areas. The Missouri Chapters of the Arthritis Foundation differed significantly from those in Kansas, Iowa, and Nebraska in the form of base funding, personnel responsible for delivering self-management programs, and the method of program promotion. Given that it is unrealistic to recommend that the funding differences between Missouri and Kansas be reconciled (i.e., garner regular state provided base funding), we recommend that the capacity of Kansas to implement PACE programs could be improved with two basic steps. First, the responsibility to develop and implement self-management programs should be distributed across a committee of volunteers led by the current paid Program Director rather than resting solely on a single paid staff member—as is the current situation. Second, the promotion of PACE programs within communities should be facilitated and supported by the Arthritis Foundation rather than leaving it to newly trained program leaders who are ill equipped to recruit participants. This facilitation and support could take the form of additional training, preparation of public service announcements, and newsletter support. It should also be noted that when compared to Nebraska, Iowa, and Missouri, the Kansas Chapter of the Arthritis Foundation is in the forefront of developing evaluation procedures and policy to determine the effectiveness of self-management programs.